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International interview:

With Professor Karola Dillenburger, Queen's University, Belfast

By Lucia Hrebenarova, Ph.D.

I had great pleasure in interviewing Prof. Karola Dillenburger from the School of Education, Queen's University Belfast, Northern Ireland. Her research concerns primarily Applied Behaviour Analysis and evidence-based decision making and intervention in Autism Spectrum Disorders. Over the years Prof. Dillenburger has been involved in a range of research projects regarding evidence-based practice, most notably in clinical psychology practice, parent training, child sex abuse, child protection, and child behaviour management. Prof. Dillenburger led the development of the online/blended Master degree in Applied Behaviour Analysis, she also co-ordinates the Masters degree in Autism Spectrum Disorders at Queen's, and collaborates with colleagues from around the world as well as the third sector in securing a number of substantial grants. She is very active and passionate in increasing awareness about evidence-based practices in the field of Autism Spectrum Disorders.

In this interview, we learn a about her impressive work and about Applied Behaviour Analysis in Europe.

Q: Prof. Dillenburger, you are the Director of the Centre for Behaviour Analysis (www.qub.ac.uk/cba). Could you please tell us about the activities and mission of the Centre?

A: The Centre for Behaviour Analysis (CBA) at the School of Education is an international research centre with associations from across QUB, other national and international Universities and Research Centres, and the local and international community. The Centre is based on a philosophy of inclusion, evidence-based effective education, and person-centred research and practice. Our mission is to provide knowledge and skills that improve confidence and competence and lead to improvements for individuals, families and caregivers, and society. We conduct research into a range of topics related to Education, Pedagogy, Curriculum, and Learning across the lifespan. We also host two Masters degree programmes, one in Applied Behaviour Analysis and one in Autism Spectrum Disorders. We offer Open Learning programmes for Registered Behavioural Technicians™ (online) and autism (on-campus) and we have an active group of doctoral students, both on-campus and distant learners.

Q: Prof. Dillenburger, could you please tell us about your academic and work-related background?

A: I grew up in Germany in a large multi-generational household. After leaving school, I trained as a Kindergarten Teacher and I worked for a few years in therapeutic settings, mainly in early years and equine assisted therapy, before going back to college to study for a Bachelors Degree in Clinical Child and Adolescent Psychology at the University of Applied Sciences in Freiburg, Germany. I moved to Northern Ireland to complete my internship and then worked there for 10 year in statutory social services, first in residential childcare and later in statutory childcare and family therapy settings. During this time, I enrolled for a part-time doctorate at the University of Ulster to study the effects of community violence on widows (Dillenburger, 1992). I was appointed by Queen's University Belfast over 23 years ago, first to lecture in the School of Social Work, where I helped to set up and run a Masters course in Applied Social Learning Theory for health and allied health staff for 15 years. About 8 years ago, I was appointed to the School of Education, where I now lead the Masters in ASD and contribute to the Masters in ABA. I represent Queen's and the Higher Education Sector on a number of Government committees and liaise with many national and international colleagues and parent

groups to ensure that evidence-based practice is available to all children and adults, especially those with disabilities, including autism.

Q: What led you into the field of Applied Behaviour Analysis?

A: My clinical training in Germany included some courses in what was then called 'behaviour modification'. I liked the clear, scientific, and transparent approach from the start, especially since most of the remainder of my clinical course was based on the psychodynamic theories of the late 1970s early 1980s, which I always found rather confusing. I am a very logical clear thinker and the inherent mentalism of psychodynamic theories simply did not make much sense to me, even then (Cooper, Heron, & Heward, 2007). After I moved to the Anglo-Irish environment of Northern Ireland, I learned more about Applied Behaviour Analysis (this term still is not widely known or used in Germany). The philosophy of Radical Behaviourism (Chiesa, 1984; Skinner, 1965, 1977) was particularly appealing as it exposes the fallacies of circular reasoning and reification of psychological terms and convinced me that this was the science to which I was to devote my professional career.

'Applied Behavior Analysis is the science in which tactics derived from the principles of behavior are applied systematically to improve socially significant behavior and experimentation is used to identify the variables responsible for behavior change. (Cooper et al., 2007).

As such Applied Behaviour Analysis offers the scientific basis for understanding the meaning and function of behaviour (of individuals, families, communities, and societies) and for achieving behaviour change, if and where desired or necessary. The behavioural insights that stem from this science can be applied to any context; clinical, educational, societal, and/or organisational. Autism interventions are a prime example of successful applications of this science employed carefully, systematically, ethically, it is highly effective and socially valid.

Q: Autism spectrum disorders are complex developmental disorders that are on increasing trend also in the Slovak republic. What is autism spectrum disorders treatment like in Europe and what treatments would you recommend to teachers and other professionals?

A: Autism spectrum disorders are diagnosed now in over 2% of children and prevalence rates are likely to continue to rise. We found that 3.5% of 11 year-old children are thought to have autism in the UK (Dillenburger, Jordan, McKerr, & Keenan, 2015). Figures are likely to be similar in the Slovak republic. Diagnosis is often delayed and parents usually worry about their child for at least a year before they go their doctor for assessment. Diagnostic assessment can take a further 6-24 months or even longer. Often children are not diagnosed until they are 5-7 years of age or older. This does not bode well for their future development, especially since we know about the importance and cost-effectiveness of early intensive behavioural interventions. For example, Motiwala, Gupta, Lilly, Ungar, and Coyte (2006) found that in 2003 in Ontario over CAN\$45million could be saved by offering ABA-based interventions early to children with an autism diagnosis. However, these interventions are not widely available in Europe, and I recommend that parents and professionals get together to promote and, if necessary, campaign for best evidence-based interventions in Slovak republic. Teachers and other professionals should demand to receive good quality training in the science of Applied Behaviour Analysis (at least at Masters level). It is vitally important that this training is delivered by Universities and backed by Government. Short one- or two-day courses are simply not enough. No other professional discipline would accept qualifications obtained on short courses.

Q: Could you please describe the basic importance of Applied Behaviour Analysis in education of children with autism spectrum disorders?

A: In the past, children with autism were considered un-educable and commonly were institutionalised, and/or pharmaceutically restrained. However, in the 1960s and 1970s behaviour analysts showed that with the right teaching methods, these children were able to learn (Ferster, 1961). Since then Applied Behaviour Analysis has become the scientific basis for evidence-based interventions. ABA based interventions usually start by identifying the behaviours or skills that children need to learn to be able to participate fully in every day activities and to make behavioural choices. At times this also includes the identification of behaviours that hinder full inclusion and that limit choices, such as self-injurious behaviours. Once the 'target behaviour' is clearly defined and quantified, it is important to discover the function of the behaviour, through a functional assessment or functional analysis. Prior to any intervention, a preference or reinforcer assessment needs to be conducted to find out what motivates the child to engage in the behaviour to be learned. The intervention then mainly focuses on setting up environmental contingencies that allow for the target behaviour to occur and be reinforced so that it generalises and is maintained in the long-term. As you can see, a lot of planning goes into the intervention and, importantly, the therapist or parent will collect data on the behaviour right from the start and throughout the intervention. As such, they will know straight away if the intervention is working (or not), and they will be able to adjust the intervention, if the target behaviour does not occur. This means that in ABA-based interventions parents are not blamed for their child's autism, rather parents are taught how to help their child develop necessary skills. Person-centred ABA-based interventions evolve with the progress of the child. ABA is not something done to a child, but it is a way of using science to involve parents and children in strategies that maximise learning outcomes.

Q: Availability of Applied Behaviour Analysis (ABA) in the Slovak republic is very limited. At this time, there are only two certified behaviour analysts in the whole country. There is no availability to study accredited study program in this field in the Slovak republic. What would you recommend to the professionals in terms of gradual implementation of the principles of ABA in our educational system?

A: The situation in Slovak republic is very similar to the situation in Northern Ireland not very long ago. The way ahead means parents and professionals working together and organising themselves into groups or organisations that focus on bringing Behaviour Analysis to the Slovak republic. Do not expect that Government to volunteer to fund ABA-based interventions without a considerable amount of lobbying. At the moment, you are lucky to have some very skilled behaviour analysts in the Slovak republic who are willing to help, however they are far too few. Of course, the Universities have an important part to play in setting up internationally approved training courses. In the meantime, you could organise conferences, parent training events, and workshops. Ask the international community for help, but beware of the 'market forces' as some people have been using the vacuum ABA expertise to make a lot of money.

Ultimately, the success of an intervention will speak for itself. However, I would advise parents to record their child's progress on video, in other words, make videos of their child's behaviour before they start the intervention and then record progress over time. There is nothing more powerful in convincing others of the effectiveness of ABA-based interventions than watching it happen right in front of your eyes.

Q: Prof. Dillenburger, you were involved in European funded projects to develop the award-winning online training resource Simple Steps. Simple Steps is now used on 9 European languages and is important in terms of educating parents and professionals. What would you consider to be the most important factors in implementing Applied Behaviour Analysis into policy and practice in the Slovak republic?

A: Working with a large team of parents and professionals to develop Simple Steps (www.stamppp.com) over many years was an amazing experience. Simple Steps is an online resource that helps parents and professionals to learn about ABA-based interventions for children on the autism spectrum. It is very easy to use and is available 24/7 to anyone who has a license to use it. It contains 8 different sections using videos and animations to explain the different concepts and it provides practical examples and exercises. Given the difficulties in many European countries of bringing ABA-based interventions to families, Simple Steps offers a wonderful resource. None of the academics involved in the development of Simple Steps have any financial interest in the resource. In other words, any money generated goes straight back to the work with the parents. There are people who care enough to put children and families ahead of profit! In a number of countries, Simple Steps is now given to parents whose children are being diagnosed. It would be important to translate Simple Steps in the Slovak language so that parents and professionals would have access to this resource. At the same time, it would be important that policy makers support the Universities setting up internationally approved ABA courses (www.bacb.com). Staff training and parent education in ABA will be the best way ahead.

Q: One of your sustained inputs into literature in the field, beside early behavioural intervention, is in relation to the parent training in autism spectrum disorders. What would you recommend to parents in the terms of increasing quality of services and evidence-based practices for their children with autism spectrum disorders in the Slovak republic?

A: Parent training and education lies at the root of evidence-based interventions. Ultimately, parents are the main advocates for their children. We have found that they are usually highly motivated to learn as much as they can about ABA and that they are keen to implement ABA-based procedures. They usually understand the practical nature of ABA very quickly because they can see the progress their child is making. Parents also are the key people to fight for the rights of their children. However, it is a tall order to ask parents to do all this on their own. Oftentimes, they are already stressed out coping with difficult behaviours of their child and lack of support from service providers. Therefore, it is very important that professionals support parents in their struggle for better services. Ultimately, it will be parents and professionals working together to improve the lives of their loved ones with autism that will make the positive difference in their lives (Dillenburger, Keenan, & Gallagher, 2015; Keenan, Kerr, & Dillenburger, 2000).

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